Preliminary Draft

HIV/AIDS Specialized Services Chapter

District of Columbia State Health Systems Plan

State Health Planning and Development Agency
District of Columbia Department

HIV/AIDS SPECIALIZED SERVICES

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HIV/AIDS SPECIALIZED SERVICES

I. INTRODUCTION

The Human Immunodeficiency Virus (HIV)/Acquired Immune Deficiency Syndrome (AIDS) is characterized by a weakened immune system that leaves the body prone to opportunistic infections that can be fatal. The first cases of AIDS in the United States were diagnosed in the early 1980s, before there was any knowledge of the disease. The Joint United Nation Program on AIDS (UNAIDS) estimates that HIV disease has caused approximately 26 million deaths and that about 42 million worldwide are HIV-positive (UNAIDS, 2002).

With the most recent AIDS case definition change in 1993 (see Attachment B), the Centers for Disease Control and Prevention (CDC) expanded the previous definition to include additional diagnoses and clinical indicators. Using the new definition, the CDC predicted a 75 percent increase over the projected number of AIDS cases in 1993 and a 10 to 20 percent increase over the projected number of AIDS cases in each subsequent year. As of December 31, 2001, 816,149 persons had been reported with AIDS in the United States, of which 362,827 were alive.

As of December 31, 2001, 174,026 individuals were living with HIV infection. (CDC Surveillance Report, Volume 13, December 2001). The CDC also estimates that each year, an additional 40,000 individuals in the United States will become infected with HIV. The CDC is able to provide these data through health reports received from various state and local health departments. Every month, the Division of Epidemiology in the HIV/AIDS Administration (HAA), D.C. Department of Health, reports to the CDC new cases of AIDS identified through active surveillance techniques and from reports submitted by District hospitals and physicians.

The HAA has teamed with the Medical Assistance Administration (MAA) to provide treatment and support services for people living with HIV/AIDS in the District. These services, available through Medicaid or Ryan White-funded initiatives, include medical and behavioral health care, medication, housing, food, employment, social services, and financial resources.

In the two decades of the HIV/AIDS epidemic, the face and nature of the disease has shifted tremendously. African American and Latino populations account for increasing proportions of people living with HIV/AIDS. The CDC estimates that 70 percent of new infections among males and 82 percent of new infections among females are African

American or Latino. Originally a disease resulting in rapid mortality, it has been transformed into a chronic disease with relatively long-life expectancy. With the advent of highly active antiretroviral therapy (HAART) in 1995, the number of new AIDS cases and deaths declined dramatically, and then stabilized at a relatively low level. However, new HIV infections occur, and the District must plan for the provision of preventive services (primary, secondary, and tertiary) as well as treatment and support services, including specialized health care for those living with AIDS.

The primary focus of this chapter is the need and implication for primary and specialized health care, as well as support services, for individuals with HIV/AIDS residing in the District of Columbia.

II. BACKGROUND AND TRENDS

A. History

With the initial emergence of AIDS in 1981, the then director of the D.C. Department of Human Services (DHS) amended Chapter 5, Title 8, District of Columbia Health Regulations to require that all AIDS cases be reported to the DHS, Commission of Public Health, effective October 1983. Also in 1983, Chapter 20, Title 29 of the D.C. Code of Municipal Regulations was amended to permit financial assistance for payment of health benefit premiums for unemployed persons infected with HIV/AIDS. In 1985, the Mayor established the Office of AIDS Activities in the Commission of Public Health, which was changed by a DHS Organizational Order to the Agency for HIV/AIDS.

The AIDS Health Care Response Emergency Act of 1985, (D.C. Act 6-123, effective December 1985) gave the Mayor the power to deal with the emergence of HIV/AIDS. This authority was later delegated to the director, DHS, in March 1986. With the re-organization of the D.C. Department of Health (DOH), this authority was transferred to the DOH director in April 2000. D.C. Act 6-156 of April 1986 required the Mayor to develop a comprehensive AIDS health care response plan, to investigate the need to establish a residential health care facility for AIDS patients, and to establish an AIDS Program Coordination Office. Several other council acts and Mayor's orders were subsequently promulgated, all dealing with specific aspects of HIV and AIDS.

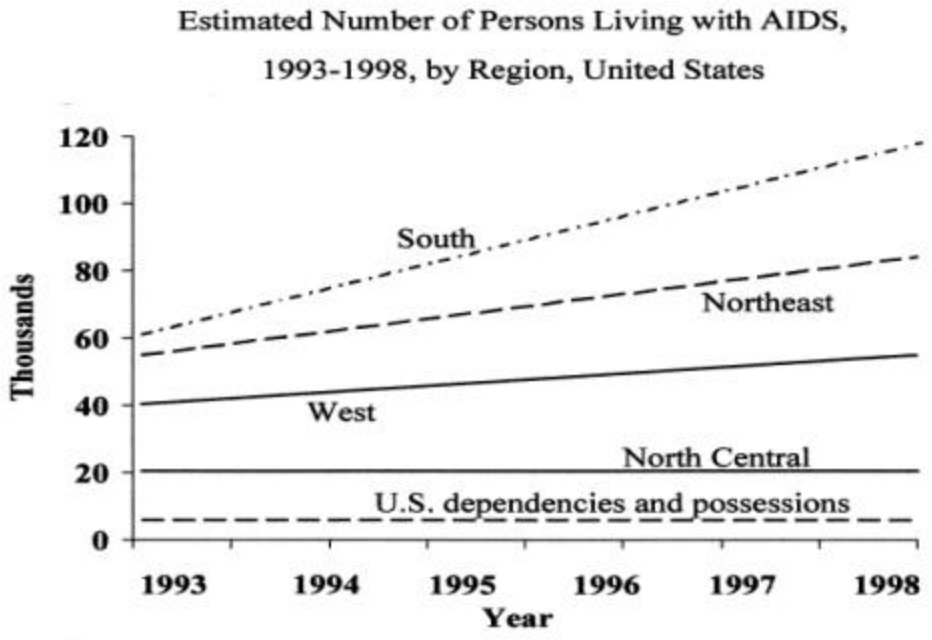
B. Prevalence and Incidence

The latest national data from the CDC indicate that in 2001 there were 43,158 AIDS cases, representing a national rate of 14.9 cases per 100,000 people. Through December 2001, the national cumulative total for AIDS cases was 816,149. In the District of

Columbia there were 870 AIDS cases in 2001, representing a rate of 152.1 cases per 100,000 people. Through December 2001, the District's cumulative total for AIDS cases were 13,969 individuals.

Figure 1 shows the estimated number of persons living with AIDS in the United States by region, from 1993 through 1998. The figure illustrates the variances across the country. The HIV/AIDS epidemic also varies within regions, states, and communities.

Figure 1.



Source: CDC *HIV Prevention Strategic Plan Through 2005*. (January 2001)

The CDC's HIV/AIDS Surveillance Report indicates that AIDS cases in the District of Columbia accounted for approximately 1.7 percent of total AIDS cases nationwide in 2001, similar to its population which represents 1.96 percent of the nation's total population. However, the District's case rate in 2001 (152.1) was 10.2 times the national case rate (14.9). In the District of Columbia and nationwide AIDS incidence has declined dramatically since 1995 due to the advent of HAART. Between 1995 and 2000, AIDS incidence declined 42 percent in the District of Columbia (see Figure 2).

Figure 2. Decline in AIDS Incidence in the District, 1995-2000

	1995	2000	Difference	
	#	#	#	%
African American/Black Males	640	347	293	45.8%
African American/Black Females	219	172	47	21.5%
White Males	159	57	102	64.2%
Hispanic/Latino Males	29	20	9	31.0%
All Other Adult Males and Females	15	20	-5	-33.3%
Total Adult Cases	**1062**	**616**	**446**	**42.0%**

As Figure 2 illustrates, the largest decline in new AIDS cases was observed in white males, (64.2 percent) followed by African American/black males, (45.8 percent), Hispanic/Latino males (31 percent), and African American females (21.5 percent). While the proportion of cases in other populations was comparatively small, it is noteworthy that these numbers actually increased during the same period.

AIDS case reporting provides a means of accurate and timely collection of AIDS case data from providers, laboratories, and health care facilities. Historically, these data provide a basis for planning and evaluating HIV/AIDS prevention and support services in the District. However, with the advent of new treatments as previously described, people with HIV are living much longer without developing AIDS-defining illness. Therefore, AIDS case data alone are no longer useful for estimating the burden of disease on the population and forecasting future trends.

In January 2001, the District of Columbia joined approximately 40 other states in passing legislation to make HIV reportable as an extension of the District's AIDS surveillance system. The District of Columbia is one of ten states that use a code-based reporting system for HIV infection. HIV cases are reportable by a unique identifier that is constructed from elements of the patient's name, demographic information, and the last four digits of the patient's social security number. Tracking of both HIV and AIDS cases will provide a better picture of the epidemic and a better basis for planning and evaluating services. Tables 1a through 1d present the number and percentage of AIDS cases, alive and cumulative, as of June 30, 2001.

Table 1a.
Number of Alive and Cumulative AIDS Cases in Washington, D.C., by Gender

GENDER	Alive	Cumulative
Adult Male	5,092 (77%)	10,537 (81%)

Adult Female	1,465 (22%)	2,331 (18%)
Pediatric	92 (1%)	172 (1%)
Total	6,649 (100%)	13,040 (100%)

Source: D.C. Department of Health HIV/AIDS Administration, June 2001

Table 1b.
Number of Alive and Cumulative AIDS Cases in Washington, D.C., by Race/Ethnicity

RACE/ETHNICITY	Alive	Cumulative
White	1,084 (16%)	2,755 (21%)
Black	5,275 (79%)	9,819 (75%)
Hispanic	251 (4%)	424 (3%)
Asian/Pacific Islander	32 (0%)	42 (0%)
American Indian/ Alaskan Native	*	5 (0%)
Undisclosed/Unknown	7 (0%)	5 (0%)
Total	6,649 (100%)	13,040 (100%)

Source: D.C. Department of Health HIV/AIDS Administration, June 2001

Table 1c.
Number of Alive and Cumulative AIDS Cases in Washington, D.C., by Age

AGE GROUP	Alive	Cumulative
0-12	92 (1%)	172 (1%)
13-19	42 (1%)	56 (0%)
20-29	1,044 (16%)	2,018 (15%)
30-39	2,793 (42%)	5,577 (43%)
40-49	2,045 (31%)	6,417 (30%)
50 and older	633 (10%)	3,850 (10%)
Total	6,649 (100%)	13,040 (100%)

Source: D.C. Department of Health HIV/AIDS Administration, June 2001

Table 1d.
Number of Alive and Cumulative AIDS Cases in Washington, D.C., by Exposure Mode

EXPOSURE MODE	Alive	Cumulative
Men Having Sex with Men (MSM)	2,808 (42%)	6,514 (50%)
Injection Drug User (IDU) and MSM	252 (4%)	617 (5%)

Male IDU	1,286 (19%)	2,325 (18%)
Female IDU	697 (10%)	1,218 (9%)
Male Heterosexual Contact	487 (7%)	691 (5%)
Female Heterosexual Contact	622 (9%)	907 (7%)
Perinatal	91 (1%)	166 (1%)
Unknown Risk	354 (5%)	482 (4%)
Undisclosed/Other	52 (1%)	120 (1%)
Total	6,649 (100%)	13,040 (100%)

Source: D.C. Department of Health HIV/AIDS Administration, June 2001

C. Mortality

According to the CDC, AIDS treatment has advanced dramatically during the past two decades, with the greatest acceleration occurring in the last five years since the introduction of multiple drug combinations to treat HIV infection. The successful treatment of HIV-infected individuals with multi-drug therapy has prevented or delayed the depletion of CD4 cells and emergence of opportunistic infections. Treatment regimens are prolonging survival for people infected with HIV by slowing or halting the progression to AIDS. This slowed progression to AIDS has been attributed to the early introduction of HAART, the use of prophylaxis against opportunistic infections, and adequate nutrition, which counters the wasting effect of AIDS. People with HIV/AIDS are living longer, more active lives and choosing to remain in the workforce or considering a return to full-time employment.

Countervailing this trend, however, are results emerging from studies recently reported from the University of California, Los Angeles. The studies estimate a significant increase by 2005 in drug-resistant HIV infections in San Francisco (*Nature Medicine*, 2001). What this portends for the District is potentially a similar increase in drug-resistant HIV, which may, according to the research team, call for the following measures:

- Delaying treatment for as long as possible to reduce side effects and development of drug resistance
- Creating centers of excellence for HIV/AIDS treatment so proper drug administration occurs
- Developing therapies for treating patients with drug-resistant viral strains.

Patterns and Trends

HIV/AIDS is having a devastating impact on communities of color, disproportionately affecting African Americans and Hispanics, as well as reaching into the Asian Pacific, Native American, and Native Alaskan communities. The epidemic continues to affect gay and bisexual men, particularly gay men of color, and has increased dramatically among African American women, intravenous drug users (IDUs), and incarcerated individuals. National data indicate that the epidemic also has had an impact among sexually active and drug-using adolescents.

During the past five to 10 years, the nature of the HIV/AIDS epidemic in the District has changed. Whereas in the first phase of the epidemic more than 60 percent of reported AIDS cases were Caucasian gay men, in 2000 African Americans accounted for nearly 79 percent of reported live AIDS cases, while Caucasians accounted for only 16 percent and Hispanics/Latinos for 3 percent. The reality of HIV/AIDS in the District for the early 2000s is that it has become a disease of racial and ethnic minorities, women, adolescents, IDUs, and young heterosexual males and females. Among African Americans, male-to-male sexual contact is responsible for the highest rate of spread, followed by IDU and heterosexual contact. The same trend is true among Hispanics/Latinos.

AIDS statistics through December 31, 2001, demonstrate the changing patterns of AIDS in the District during the past decade. Table 2 illustrates the nature of the AIDS epidemic in the District.

The District's AIDS data indicate that AIDS incidence among women continues to increase faster than among men, with the highest number of AIDS cases among African American females.

The majority of AIDS cases among women are attributed to IDU, with an increasing number associated with heterosexual contact. A particular category of interest is the AIDS cases among women of childbearing age (ages 13-45) among whom there have been significant increases.

Young African American and Hispanic men having sex with men (MSM) remain at a high risk for HIV infection. AIDS cases among District Hispanic men remain low and relatively stable, with MSM accounting for 72 percent of such cases, IDU accounting for 7 percent, and heterosexual contact accounting for 10 percent. Based on AIDS surveillance data, the HAA prepared Table 3, showing selected vulnerable populations in

the District of Columbia.

Table 2. Selected Longitudinal Data for the District

Category	Comparison Year(s)	Most Recent Year(s)
Overall cases		
Cumulative D.C. residents reported/living with AIDS	1983: 21/2	1990: 2,706/461
Female percent of diagnosed AIDS cases	1996: 22%	1997-2000: 28%
Male diagnosed cases, IDU mode	1996: 31%	2000: 23%
Female diagnosed cases, IDU mode	1996: 52%	2000: 31%
Male, heterosexual contact mode	1990-1995: 6%	1996-2000: 12%
Female, heterosexual contract mode	1990-1995: 36%	1996-2000: 44%
MSM mode, total cases / with AIDS	1990-1994: 52% / 63%	1995-1999: 36% / 49%
AIDS cases, MSM, among Blacks/African Americans	1989: approx 50%	1996: over 70%

D. Funding for HIV/AIDS Treatment

As the HIV/AIDS epidemic expands and newer, more effective treatments become available, access to medical benefits and services becomes a critical issue. Currently, individuals living with HIV/AIDS have two options for public assistance if they are unable to bear the cost of treatment: Medicaid and Ryan White-funded initiatives. Both of these public assistance programs are characterized by their own eligibility criteria and funding limitations.

Table 3. Selected Vulnerable Populations in the District of Columbia

Population Category	Profile		Mode of Transmission	
Adolescents and young adults with AIDS	African American Male	84% 68 %	MSM Heterosexual contact IDU	47% 30% 11%
Incarcerated	African American Male	98% 88%	IDU MSM Heterosexual contact	70% 14% 7%
Homeless with AIDS	African American Male	89% 84%	IDU MSM Heterosexual contact	42% 25% 17%

1. Medicaid

Title XIX of the Social Security Act is a program that provides medical assistance for certain individuals and families with low incomes and resources. The program, known as Medicaid, became law in 1965 as a jointly funded cooperative venture between the federal and state governments to assist states in providing adequate medical care to eligible needy persons. Within broad national guidelines set by the federal government, states can establish their own eligibility standards; determine the type, amount, duration, and scope of services; set the rate of payment for services; and administer their own program. Individuals whose illness has progressed to AIDS are eligible to receive Medicaid benefits under the eligibility category for disability. However, Medicaid enrollment is limited by stringent financial and medical eligibility requirements and is unable to extend health care coverage to people living with HIV who cannot afford needed medical care yet do not meet the eligibility requirements.

2. Ryan White CARE Act

Over the past decade, considerable government attention has been paid to the problem of meeting public health prevention and treatment needs. Solutions include allocating financial resources to provide public assistance to cover the high costs of treatment among populations unable to bear the cost. On August 18, 1990, Congress enacted Public Law 101-381, the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act to enable states to provide health care to people living with HIV/AIDS who are ineligible for Medicaid. This legislation was reauthorized on May 20, 1996, as Public Law 104-146, the Ryan White CARE Act Amendments of 1996, and again on October 20, 2000, as Public Law 106-345. The CARE Act represents the largest dollar investment the federal government has made to date specifically for the provision of services to people living with HIV disease.

The Ryan White CARE Act directs monetary assistance to the following:

- Eligible Metropolitan Areas (EMAs) with the largest numbers of reported cases of AIDS, to meet emergency needs of people living with HIV disease (Title I)

- All states to improve the quality, availability, and organization of health care and support services for individuals living with HIV disease and their families (Title II)

- Public and nonprofit entities to support early intervention services for people living with HIV disease (Title III)

- Clinical research laboratories that focus on therapies for children with HIV disease and pregnant women with HIV, and health care to children and their families (Title IV)

- AIDS Education and Training Centers, Special Projects of National Significance, and dental reimbursement (Part F).

3. *AIDS Drug Assistance Program (ADAP)*

Under Title II of the CARE Act, formula grants are awarded to the states and other eligible areas to improve the quality, availability, and organization of HIV health care and support services. In addition, the AIDS Drug Assistance Program (ADAP) is funded to provide medications to low-income individuals with HIV disease who have limited or no coverage from private insurance or Medicaid, in all 50 states, the District of Columbia, Puerto Rico, the Virgin Islands, and Guam.

For fiscal year 2001, the states projected that approximately 137,800 individuals with HIV disease who have limited or no coverage from private insurance or Medicaid would access ADAP. At any one time, the national ADAP anticipates serving 79,000 people. Because protease inhibitors (PIs) and other antiretroviral medications have proven to be very effective when used in combination, demand for combination therapy has grown rapidly, not only among individuals already in care, but also among those who had not previously sought treatment.

Due to the cost of combination therapy being high—between $10,000 and $12,000 a year per person—ADAPs are greatly challenged in responding to the increased client demand. Additionally, the rapid growth of the HIV epidemic among poor and historically underserved populations, and the evolving treatment standards which involve more than one antiviral drug, have contributed to these strains. In addition, the number of people seeking and receiving treatment for HIV and AIDS continues to increase on a monthly basis.

E. Significant and Emerging Issues

1. HIV Case Surveillance

Mandatory AIDS reporting, already in place, provides a means of accurate and timely collection of AIDS incidence and prevalence data, but not of HIV data. The District's Mayor and the Council of the District of Columbia have approved HIV reporting for

implementation, which is essential in identifying the current and future trends of HIV disease. The District's method for HIV reporting using the unique identifier system was planned for full implementation by December 2001. Tracking of both HIV and AIDS cases will provide a more complete epidemiological profile of the syndrome and provide a better basis for planning and budgeting.

Issues of confidentiality have a significant impact on collecting HIV/AIDS data, and nationwide, health departments have sought to maintain a sensitive balance between the need for essential epidemiological data and the need to protect personal medical confidentiality. Unlike in cases of AIDS and other sexually transmitted diseases (STDs) where surveillance is conducted using client names, HIV surveillance elicited considerable protest from various segments of the community who were afraid of confidentiality breaches. As a compromise, the District elected to conduct HIV case surveillance using a system of unique identifiers, rather than names.

The primary reason for HIV case reporting is to protect and maintain public health, as well as to enable the DOH to track the epidemic and judiciously allocate scarce resources where it will do the most good. Case reporting will allow for early medical intervention and treatment of persons infected with HIV disease. Additionally, the neighboring jurisdictions of Maryland and Virginia both require the reporting of HIV cases to their respective Departments of Health and provide partner notification services for clients who test HIV-positive.

Finally, given anticipated trends in the Department of Health and Human Services, the adoption of HIV case surveillance, resulting in the identification of all new cases of HIV, will be beneficial in increasing funding to eligible jurisdictions for the provision of care to infected individuals under the Ryan White CARE Act. Implementation of the HIV case surveillance program by HAA began in January 2002.

2. *Integration into Mainstream Care*

As the treatment of AIDS as a chronic condition over long periods of time increases, issues of how such care can be integrated into the mainstream health care system rise to the forefront. The provision of a continuum of care to those in the early stages of the disease is an emerging issue in the care and treatment of HIV/AIDS. The focus should be to get people to voluntarily test for HIV and to counsel them to enroll in medical care as soon as possible if they test positive. Providing primary care and drug therapy early in the stages of infection may delay or prevent low CD4 counts and opportunistic infections, and may ultimately be less costly to the community.

Cooperation among public and private institutions and primary care providers is essential to meet the broad spectrum of needs of persons in the early stages of the infection. For these clients there is a need for the development of a comprehensive care plan, updated regularly, to cover different service needs such as baseline medical work-up, ongoing medical management, and social services needs that include housing, food, employment, or job training. Through early intervention the community can avoid the high cost later-stage care that may be as high as $20,000 per person per year.

3. Collaborative Efforts – HAA and MAA

Through the collaborative efforts of the HAA and MAA, the District is aggressively addressing the comprehensive needs of its residents living with HIV/AIDS. HAA continues its focus to meet the needs of individuals infected with HIV/AIDS: medical treatment, case management, housing, pharmaceutical services, nutrition and food bank services, child care, transportation, behavioral health services, and the like. Through funds provided by the Ryan White CARE Act, HAA is able to meet health and support services needs of uninsured and underinsured people living with HIV/AIDS.

The Medical Assistance Administration is the District's administrator of the public insurance program that provides primary health care coverage for uninsured and underinsured District residents. Working collaboratively, HAA and MAA developed Medicaid-based HIV initiatives that expand health care coverage to HIV positive District residents. Expansion of Medicaid coverage to HIV positive residents permits the use of Ryan White CARE Act (RWCA) funds to identify and cover difficult-to-reach and previously ineligible populations, as well as relieve pressure on the local ADAP.

Medicaid-based HIV initiatives include the following:

- Ticket to Work II A Demonstration – This program will serve approximately 420 HIV-infected clients, cost approximately $5.8 million in year 1 and over $39.6 million over six years. It will operate as a capped Medicaid fee-for-service expansion. Client characteristics will include clinical indicators such as elevated viral loads and history of symptomatic HIV disease combined with income levels at or below 300 percent of the federal poverty level. The individual will not be eligible for other entitlements, while lacking adequate insurance and working at a minimum of 40 plus hours per month.

- 1115 HIV Medicaid Expansion Waiver – Approved January 2001, this focuses on District residents who are ineligible for other entitlements and living at or below 100 percent of the federal poverty level. Clients enrolled in the waiver program

will have access to the full array of Medicaid benefits offered by the District, including a comprehensive prescription drug benefit.

- The 1915(c) Waiver – This program currently provides water filters to individuals who are severely immuno-compromised, and it will be expanded. The HAA and MAA are working together to enlarge both the scope of covered services and the eligibility criteria. This expansion may allow the District to serve many more individuals in need of home- and community-based services, which have proven to be both cost-effective and of high quality. Additionally, the program affords the District the opportunity to provide clinically informed case management and other care coordination to HIV-infected Medicaid enrollees. At the same time, the expansion of the waiver may relieve funding pressure on the RWCA programs by leveraging additional federal resources via Medicaid.

These initiatives allow early intervention with comprehensive health care benefits, including clinical and lab monitoring, and will provide longitudinal utilization data from a prospectively identified HIV-infected client population.

The major strength of this collaboration is the maximization of the expertise and experience of two disparate organizations to achieve the overarching goal to meet the health and basic life needs of District residents living with HIV/AIDS.

4. Emerging Therapies

Multiple drug therapy, which includes the use of Protease Inhibitors and other antiretroviral agents, is beginning to redefine HIV/AIDS as a chronic disease, rather than as a terminal disease. A combination of new drug therapies and a desire to live healthy lives have resulted in individuals surviving for 15 years or more after initial diagnosis. Many individuals have remained HIV positive without any conversion to AIDS. Thus, with good care many individuals may live a long, healthy life. Indeed, participants at several HIV/AIDS conferences have suggested that it may be possible to eradicate the virus from the body and completely suppress it by using a combination of new HIV drugs. As noted previously, this optimism must be tempered by emergence of HIV drug-resistant strains.

Most researchers believe that these drugs may continue to transform HIV from a terminal disease into a chronic disease, not unlike diabetes or heart disease. However, researchers agree that the success of these drugs depends upon starting treatment early and complying with the drug therapy regimens. Starting treatment early will depend on regular HIV testing, invitation of HIV positive individuals to register for drug therapies,

availability of support services, and support for therapy adherence. Early initiation of treatment will occur only when individuals are tested and know their HIV status and agree to the treatment regimen.

III. SUMMARY RESOURCE INVENTORY AND HISTORICAL UTILIZATION OF SERVICES

Table 4 itemizes the HAA-approved Year 11 Title I Ryan White and appropriated vendors for 2001. Vendor services are described in aggregate form following the table.

A. Resources for Delivery of Acute Care

The District of Columbia at the end of 2002 has 9 acute care hospitals with acute care facilities available to HIV positive clients who have Medicaid or other insurance and to HIV positive persons who have no insurance provided that they are registered with primary care providers who can refer them to inpatient acute care when needed.

Table 4. HAA-approved Year 11, Title I Appropriated Vendors for 2001

- Children's National Medical Center
- D.C. General Hospital
- George Washington University Hospital
- Georgetown University Hospital
- Greater Southeast Hospital
- Hadley Memorial Hospital
- Howard University Hospital
- National Rehabilitation Hospital
- Providence Hospital
- Sibley Memorial Hospital
- Washington Hospital Center

B. Resources for Delivery of Non-acute Care

Non-acute care encompasses a range of medical and health services that are designed to enhance the client's health and are provided inside or outside a hospital setting. The District has the following resources for delivering non-acute care:

- Primary medical care is provided by physicians and nurse practitioners at 12 AIDS services organizations.

- Dental care is provided by dentists and dental technicians at three AIDS services organizations.

- Mental health care is provided by psychiatrists, psychologists, and mental health counselors at seven AIDS services organizations.

- Substance abuse treatment and counseling services are provided by psychiatrists, psychologists, and substance abuse counselors at six AIDS services organizations.

C. Resources for Delivery of Support Services

Support services are not medical or health services, but rather aim to further enhance the client's health and quality of life. The following are examples of these types of services provided in the District:

- Case management is provided by social workers and case managers at 15 AIDS service organizations.

- Nutritional counseling services are provided by nutritionists and nutritional counselors at seven AIDS service organizations.

- Food bank and home-delivered grocery services are provided by volunteer staff at four AIDS service organizations.

- Treatment specialist services are provided by nurses and other appropriately trained staff at three AIDS service organizations. Treatment specialists work with clients to ensure that they understand the ramifications of the drugs they utilize in clinical trials and in their own medication therapy.

- Each of the following support services is provided by two AIDS service organizations
  - Babysitting
  - Home health care/home health nursing services
  - Emergency drug assistance
  - Day treatment
  - Peer and paraprofessional counseling
  - Legal counseling services

- Each of the following support services is provided by one AIDS service organization
  - Home-delivered meals
  - Bereavement services
  - Complementary therapy
  - Discharge planning
  - Permanency planning

- Crisis intervention
- Outreach/referral service

D. Resources for the AIDS Drug Assistance Program

In the District of Columbia, ADAP provides medication to an average of 650 to 850 clients per month, at a total annual cost in fiscal year 2000 of $9.1 million. ADAP is provided to District clients through a network of 14 existing pharmacies that have been strategically selected for their location and accessibility to clients. Many ADAPs, including the District of Columbia ADAP, were established to operate under a pharmacy reimbursement model similar to Medicaid. This allows patients to go to a participating pharmacy, show their ADAP cards, and have their prescriptions filled.

As the number of FDA-approved HIV treatments has increased, states have added some or all of the newer drugs within the limits of available resources. The availability of new, effective drugs, combined with the greatly increased cost of new medications, has affected the expansion of formularies. States determine which drugs to include on their formularies. The District of Columbia has virtually all antiretroviral medications and many OI prescription drugs on its formulary. The District does not have a strict income eligibility criterion, but requires individuals who meet the income threshold simply to provide proof of their HIV status.

E. Utilization of Services in Fiscal Year 2000

The HAA tracks service utilization through its client-level services utilization database METROCARES. For services funded under the RWCA, the unduplicated count of users of such services and actual service units accessed is provided in Table 5.

Table 5. Utilization of Selected HIV/AIDS Services in FY2000

Type of Service	Number of Users	Number of Service Units
Primary Medical Care	2628	15392
Dental Care Services	515	1334
Mental Health Services	2986	8850
Substance Abuse/Therapy/ Counseling	3606	9940
Face-to-Face Case Management	2080	9355
Other Case Management	2051	45659
Paraprofessional Counseling	55	402

Specialist Care	22	1318
Other Counseling	407	2928
Day/Respite Care	138	392
Housing Assistance	97	1558
Food Bank/Home-Delivered Meals	1000	7543
Transportation Services	249	6136

IV. PROJECTIONS

This section includes an overview of the methods used to estimate the need for selected HIV/AIDS services. Projections are made for the following eight services: primary medical care, dental care, mental health, substance abuse/therapy/counseling, case management, day/respite care, food bank/home delivered meals, and transportation services.

As the model demonstrates, the demand for critical services is expected to more than double over the next five years.

A. Methods

A simple model was used to project the likely change in demand for HIV/AIDS services in the District. In this model, the intensity of service use is assumed to remain constant for the HIV/AIDS population. Further, only RWCA-funded service utilization data were available for this analysis and, as a result, total HIV/AIDS service utilization in the District may be considerably understated. Even with these simplifying assumptions, the model illustrates the likely effect of the growth in the local epidemic on the demand for HIV/AIDS services.

Table 6 provides a breakdown of the demographics, age-groupings, insurance status of HIV/AIDS clients utilizing services in fiscal year 2000. Table 7 provides a historical look at AIDS prevalence in the District from 1996 to 2000. These estimates reflect the number of individuals living in the District with AIDS, adjusted for reporting delays and death.

Table 6. Demographics, Age-Grouping and Insurance Status of HIV/AIDS Clients Utilizing Services in Fiscal Year 2000

Gender (HIV+, not AIDS)	
Male	2029
Female	1148
Other/Unknown	7
Total	3258
Gender (AIDS diagnosis)	
Male	724
Female	331
Other/Unknown	7
Total	1069
Gender (Unknown illness stage)	
Male	1785
Female	1256
Other/Unknown	15
Total	3056
Race/Ethnicity (HIV+, not AIDS)	
White	263
Black	2709
Hispanic	157
API	8
AI/NA/E/A	6
Unknown	102
Total	3258
Race/Ethnicity (AIDS defined)	
White	72
Black	926
Hispanic	59
API	1
AI/NA/E/A	0
Unknown	11
Total	1069
Race/Ethnicity (Unknown illness stage)	
White	270
Black	2617
Hispanic	96

API	9
AI/NA/E/A	4
Unknown	48
Total	3056

Age Groupings of HIV/AIDS Clients Utilizing Services in FY 2000

HIV, not AIDS	Age Group	Number of Clients
	0-13 years old	81
	14-19 years old	34
	20-24 years old	119
	25-29 years old	258
	30-34 years old	452
	35-39 years old	678
	40-44 years old	667
	45-49 years old	520
	50-54 years old	250
	55 years and older	184
	Unknown	15
	Total	3258
AIDS diagnosis		
	0-13 years old	63
	14-19 years old	3
	20-24 years old	9
	25-29 years old	56
	30-34 years old	117
	35-39 years old	195
	40-44 years old	248
	45-49 years old	194
	50-54 years old	107
	55 years and older	69
	Unknown	8
	Total	1069
Unknown illness stage		
	0-13 years old	82
	14-19 years old	37
	20-24 years old	111
	25-29 years old	182
	30-34 years old	353
	35-39 years old	591
	40-44 years old	611
	45-49 years old	445

50-54 years old	254
55 years and older	135
Unknown	255
Total	3056

Insurance Status of HIV/AIDS Clients Utilizing Services in FY 2000

HIV+, not AIDS		
	Private Insurance	283
	Medicaid	771
	Other Public Insurance	698
	No Insurance Coverage	1256
	Unknown Insurance Status	250
	Total	3258
AIDS diagnosed		
	Private Insurance	61
	Medicaid	347
	Other Public Insurance	79
	No Insurance Coverage	316
	Unknown Insurance Status	266
	Total	1069
Unknown illness stage		
	Private Insurance	136
	Medicaid	271
	Other Public Insurance	244
	No Insurance Coverage	605
	Unknown Insurance Status	1800
	Total	3056

Household Income of HIV/AIDS Clients Utilizing Services in FY 2000

HIV+, not AIDS		
	Below 300% of poverty	2103
	At 300% of poverty or above	125
	Unknown	1030
	Total	3258
AIDS diagnosed		
	Below 300% of poverty	673
	At 300% of poverty or above	19
	Unknown	377
	Total	1069
Unknown illness stage		
	Below 300% of poverty	1247
	At 300% of poverty or above	62
	Unknown	1747
	Total	3056

Table 7. Living AIDS Cases in the District of Columbia

Year	AIDS Live Cases	Annual Increase
1996	3,889	--
1997	4,461	14.7%
1998	5,172	15.9%
1999	5,746	11.1%
2000	6,473	12.7%
2001	7,788	16.9%

Using a broad assumption about the s-shaped epidemic curve, the model projected the number of living AIDS cases in the District. Based on the AIDS prevalence data provided above, estimates for the increase in AIDS prevalence for the next five years are presented in Table 8. Because HIV surveillance is as yet unreliable, projections are based on an assumption that HIV and AIDS prevalence remains in constant proportion.

Table 8. Estimated Increase in AIDS Prevalence in the District, 2003-2007

Year	Estimated Annual Increase
2003	13.0%
2004	13.0%
2005	12.5%
2006	12.5%
2007	12.0%

B. Projections

Projections for 2004 and 2005 are presented in Table 9.

Table 9. Service Unit Projections for 2004 and 2005 (See APPENDIX E)

C. Discussion

As the model demonstrates, the demand for critical services is expected to grow in excess of 230 percent over the next five years. As the population with HIV/AIDS continues to live longer, the demand for psychosocial services may increase by more than these estimates suggest. Current areas of shortage (e.g., case management) will be overwhelmed in the absence of additional service capacity and new funding resources. Additionally, this population will likely require more involved outpatient and lab diagnostic monitoring as individuals become treatment experienced and their medication regimens grow in complexity. Clearly, then, there is a need for a greater number of properly trained, HIV-experienced clinicians and medical staff.

As noted, the model is limited by several simplifying assumptions. Yet, the premise that the growth in the local epidemic will largely drive the demand for services is largely valid. This model, then, serves a valuable function in illustrating the magnitude in the increase in demand for RWCA-funded services over a relatively short time period.

The critical policy message is that additional resources will be required. Unfortunately, funding for this population remains limited even with such dramatic increases in need. Federal appropriations under the RWCA are likely to remain constant over the period. Cognizant of this danger, HAA and MAA have begun to more closely coordinate their programs in order to leverage the maximum amount of federal resources available for persons with HIV/AIDS. The 1115 and Ticket to Work Medicaid Demonstrations represent concrete actions in this regard; continued collaboration between HAA and MAA on the 1915(c) Medicaid waiver and 1902(r)2 Medicaid expansion provisions are also vital.

While these programs will have an impact on the District's budget, they may forestall many individuals from turning to the Health Care Safety Net Administration (HCSNA)/Alliance for their care. This is critical because the HCSNA/Alliance liabilities for HIV medical care are potentially quite large and the HCSNA/Alliance, unlike Medicaid, receives no federal match. The policy initiatives under discussion would enroll many such individuals into Medicaid, capturing the 70 percent federal match and allowing clients to choose their provider. Thus, the current HAA-MAA collaborative represents a critical initiative that may preserve patient choice, sustain private providers, and dramatically reduce District liabilities.

V. CRITERIA AND STANDARDS

Individuals living with HIV/AIDS are considered to have a chronic medical condition that requires consistent and periodic medical management. They may need a variety of medical services during their lifetime, including frequent primary care visits for monitoring of blood levels, medication management, treatment for non-acute and acute illness, some requiring hospitalization for HIV/AIDS-related and non-related medical-surgical problems. Other medical services may include rehabilitation, home health, and/or behavioral health services. The same providers that render services to other patients with acute and/or chronic illnesses may often provide the patient with HIV/AIDS medical and behavioral health care needs. This section focuses on the specialized needs of individuals with HIV/AIDS, specifically, the need for providers specializing in HIV/AIDS.

A. Availability

Availability of care may be defined as the presence of enough numbers of primary care (quantity) and specialist care (quality) providers to meet the health care needs of people living with HIV/AIDS in the particular jurisdiction, such that clients do not have to travel outside their jurisdictions for care.

As of December 2002, most of the District's nine acute care facilities are staffed with medical specialists with considerable experience in HIV care. They are available to treat HIV positive clients who have Medicaid or other insurance and are also available to treat HIV positive persons who have no insurance if they are registered with primary care providers who can refer them to inpatient acute care when needed.

The HIV Cost Services and Utilization Study (HCSUS) reported that a majority of people with

HIV/AIDS received their care from providers specializing in HIV/AIDS. About a third received their care from major teaching hospitals, approximately 39 percent received care from HIV treatment centers that are not teaching institutions, while the remainder (about 28 percent) received their care in other health care settings.

In Washington, D.C., an eligible metropolitan area (EMA), through RWCA funding, there are 56 organizations serving HIV/AIDS clients, 28 in Washington, D.C., nine in Maryland, 18 in Virginia, and one in West Virginia. It is clear that 9 acute care hospitals, some of which are included among the 56 provider organizations, are enough to ensure the availability of adequate care for District residents living with HIV/AIDS.

The HAA is not aware that any District resident living with HIV/AIDS has traveled outside of the EMA to receive specialized care. There may, however, be a shortage of non-specialist HIV/AIDS providers. Of the 12 AIDS services organizations funded by the RWCA to provide primary medical care, only one is a hospital. Given the current number of live AIDS cases (7,788 cases), as well as the current HIV prevalence estimate (12,000 to 14,000 cases), there is a valid concern that there may be an insufficient number of providers specializing in HIV/AIDS treatment. The most significant need for specialized care is among the primary care providers. Although HAA's RWCA-funded vendors are considered HIV specialists, meeting the federal criteria of experience and population served, other providers that serve District residents with HIV/AIDS may not have the same level of experience or expertise.

Managed care organizations (MCOs) that have contracts with D.C. Medicaid must demonstrate evidence of a sufficient number of contracted providers in the network that can treat the specific needs of clients with HIV/AIDS. Access and availability standards include appointment times for routine and urgent visits and locations within 30 minutes access by public transportation.

B. Accessibility

Accessibility of care, often referred to as access, should not be confused with availability of care. Accessibility is a measure of the presence or absence of barriers to health care utilization. Such barriers may manifest themselves as absence of health insurance, high cost of care, physical distance between a client and his/her provider, inconvenient clinic hours, language or cultural barriers, or a lack of sensitivity by care providers. Any problem that prevents a client from utilizing care when that care is available impacts on accessibility.

1. *Lack of Health Insurance*

The RWCA attempts to assure health coverage to individuals who are HIV positive and who are either uninsured or underinsured. In the District, some degree of health care coverage is provided to clients who cannot afford to pay for it, through Medicaid (if they are eligible), the Alliance, or RWCA funds. Still, some degree of no insurance or underinsurance persists among those who are HIV infected. The Medicaid-based HIV initiatives aim to substantially lower this rate, though the department recognizes that these represent only partial solutions in the presence of such great need.

2. *High Cost of Care*

The high costs of care for HIV-positive individuals may be less of a barrier in the District than in other jurisdictions because District residents are assured of health care coverage through Medicaid (if eligible) or RWCA. However, limitations in dental, mental health, substance abuse, and other types of coverage may result in substantial medical liabilities for some clients. Further, the lack of awareness about eligibility and coverage options may result in large financial barriers to many.

3. *Physical Distance to Provider Offices*

The District's HAA has a policy of ensuring that the location of health care and support services providers is geographically distributed. In some cases, providers are encouraged to establish satellite offices in locations where they did not have a presence. This policy is designed to minimize the physical distance that clients have to travel to obtain the services they require.

4. *Clinic Hours*

The HAA has a policy of encouraging service providers to keep their clinics open on weekends and in the evenings. This is designed to ensure that clients have as much opportunity to make and keep appointments as possible.

5. *Language and Cultural Barriers*

The HAA recognizes that in the District of Columbia, which is more culturally diverse than most other EMAs, there is a need to provide services in an atmosphere that is linguistically and culturally appropriate. Service providers are therefore encouraged and sometimes required to show cultural and linguistic diversity among their staff, especially among frontline staff who have daily interactions with clients.

6. *Sensitivity Training*

The HAA recognizes the need for sensitivity among staff who provide services to people living with HIV/AIDS. It has a policy of encouraging providers to ensure that their staff members undergo sensitivity training. In situations where clients report provider insensitivity, the HAA will ensure that such insensitivity is addressed.

C. Continuity

The requirement for a continuum of care for individuals living with HIV/AIDS is similar to that for other individuals with chronic illnesses. The care continuum for HIV/AIDS clients may include, in addition to medical services, mental health treatment, substance abuse treatment, case management, and various socioeconomic support services.

D. Quality

The management of care for people with HIV requires a high level of expertise that enables the care provider to manage the complexity of the illness. Expertise in HIV care management includes competency in the prescription of antiretroviral therapy and the ability to keep up with the rapid pace of evolution of the scientific and clinical knowledge related to the treatment and management of the HIV disease. Currently, there are no formal criteria to certify providers as

HIV specialists, although there are efforts by the MAA to develop local definitions and criteria. The New York AIDS Institute has already developed a policy to articulate standards for defining an HIV specialist and to guide clinical providers and health care facilities in development and implementation of their own procedures for credentialing HIV specialists.

In accordance with guidelines from the Health Resources and Services Administration (HRSA), the HAA requires each service provider to establish a formal quality of care program that fosters a quality improvement philosophy as part of the HIV service delivery program. Each provider is required to establish a mechanism for the following:

- Development of a quality improvement plan that clearly indicates responsibilities and accountability and defines a process for ongoing evaluation and assessment.

- Performance measurement of clearly defined indicators with plans for follow-up of results and a statement of desired health outcomes. Indicators should include clinical performance, case management, and other services as prioritized by the program.

- Quality improvement activities conducted by cross-functional teams, with action steps and a mechanism for integrating change into routine activities.

- Inclusion of patients in quality-related activities.

- Provisions for ongoing education of staff about quality improvement, support for staff involvement in quality improvement activities, and integration of involvement in quality improvement activities into job expectation.

E. Acceptability

The HAA has developed standards and guidelines on HIV counseling after consultation between outside experts and the CDC staff. The two levels of guidance provided are as follows:

- Standards shall be consistently applied to the delivery of HIV counseling and testing services and must be followed in virtually all cases.

- Guidelines shall be more flexible. They should be followed in most cases. However, depending on the client, setting, and other factors, guidelines can and should be tailored to fit individual needs.

HAA has developed and published standards and guidelines related to the following:

- Program Standards and Guidelines
  - Client eligibility criteria
  - Risk assessment development
  - Referral service development
  - Quality assurance
  - Publicly funded programs

  - Data collection and analysis

- Counselor and Provider Standards and Guidelines
  - Risk assessment
  - HIV-prevention counseling
  - Notification of HIV results and prevention counseling
  - Counseling and repeat testing
  - Referral process

F. Cost

Medical care for HIV/AIDS includes, at a minimum, monthly primary care physician office visits, prophylaxis and treatment medications, and periodic laboratory testing for CD4 and viral load counts. In 1998, the direct medical care costs for an individual with HIV/AIDS was approximately $20,000 per year (HCSUS). With the advent and availability of new medications, current medical care costs are assumed to be, at a minimum, consistent with the 1998 estimates.

Medicaid and Medicare provide health care benefits for District residents who meet eligibility requirements. Both public insurance programs cover inpatient and outpatient services. Medicaid however provides only prescription drug coverage. Nationally, Medicaid covers roughly one-half or more of all AIDS spending. Both of these public-financed coverage programs generally target those who are relatively advanced in disease and are therefore disabled.

Clients enrolled in Medicaid managed care programs (e.g., pregnant women and low-income parents) may have more extensive covered benefits and better continuity of care. Although HIV-infected individuals have the right to opt out, they are encouraged to remain in Medicaid managed care. One concern, however, is the perceived limited number of specialized HIV/AIDS providers. However, recent contractual requirements specify that MCOs demonstrate a network of qualified HIV/AIDS providers.

Commercial insurers usually issue a certificate of coverage, which outlines the health benefits and lifetime limits. Chronically ill persons, regardless of their illness, must be aware of the limitations of their benefits to avoid disruption in care and/or medication.

RWCA provides coverage to people with HIV/AIDS who are unable to access health coverage through other resources, including Medicaid, Medicare, underinsured, and commercial payer sources. For this reason, the RWCA is considered the payer of last resort. One program of particular importance is the ADAP, which covers HIV-related prescription medications. This program therefore serves a critical "wrap-around" to both public and privately financed coverage.

VI. GOALS AND OBJECTIVES

The following goals, objectives, and recommendations were developed to reflect the specialized health care needs of individuals with HIV/AIDS. They are not intended to supplant HAA's detailed strategic plan, but rather to address the specific issues identified by agencies and providers specifically related to this State Health Systems Plan.

Goal 1:

Coordinate needed medical, psychological, social, and work/vocational educational services for all District residents with HIV/AIDS regardless of payer source.

Objectives:

1.1: Provide case management services to District residents with HIV/AIDS including a single point of contact that assists in the planning and implementation and follow-up of services that permits the optimum health and functioning for the person living with HIV/AIDS.

1.2 Increase the number of case management services, support services, and social services to meet the demand of persons living with HIV/AIDS.

Goal 2:

Identify funding resources for health care and related services to all District residents with HIV/AIDS.

2.1: Provide services through the Ryan White CARE Act funding to District residents with HIV/AIDS with no other sources of financial support for prevention and treatment services, including case management, medical, behavioral health, pharmaceutical, housing, and other social services.

2.2 Continue collaborative efforts between HAA and MAA to coordinate health benefits for District residents through early identification of eligibility for Medicaid programs and the Ticket to Work Medicaid Demonstrations. Continue to pursue expansion of care services under Medicaid Demonstrations and waivers in order to leverage additional federal monies to fund care currently funded by local appropriated dollars.

Goal 3:

Provide culturally competent physical and behavioral health care services to individuals with HIV/AIDS regardless of race, gender, age, political affiliation, religion, payer source, income level, residency status, disability, and/or sexual preference.

Objectives:

3.1: Evaluate clients perception of provider cultural sensitivity/competence through annual patient satisfaction surveys.

3.2 Ensure that providers offer cultural sensitivity education programs to their staff and periodically evaluate their performance as reported in annual patient satisfaction surveys that address perceptions of provider's cultural sensitivity or competence. Health and managed care organizations annually conduct patient satisfaction surveys.

Goal 4:

Provide mental health and substance abuse evaluation and access to treatment to individuals with HIV/AIDS to ensure effective and adequate delivery of care.

Objectives:

4.1: Incorporate mental health and substance abuse screenings by providers at the time of the annual primary care visit for individuals with HIV/AIDS.

4.2: Provide a referral and communication process between primary care providers and behavioral health clinicians.

4.3. Develop a universal behavioral health screening tool for primary care physicians or other providers specializing in treating people with HIV/AIDS to assist in the early identification of mental health and substance abuse disorders.

Goal 5:

Achieve at least an 80 percent adherence to medication treatment regimes by individuals with HIV/AIDS.

Objectives:

5.1: Develop a system that enables HIV/AIDS patients to adhere to the prescribed medication treatment plan.

5.2: Provide individuals with ready access to the prescribed medications, including mail orders, multiple months of prescriptions, and pharmacies within the neighborhood where the individual resides.

5.3: Provide periodic medication education to individuals to encourage individuals to adhere to their treatment regime.

5.4

Develop a collaborative among consumers, providers, and HAA to implement strategies to assist HIV/AIDS clients in medication adherence.

Goal 6:

Ensure that all District residents with HIV/AIDS have access to HIV specialist providers, including primary care, pediatricians, and obstetricians.

Objectives:

6.1: Implement adoption of HIV specialist criteria, including biannual certification assessment, as established by HAA and federal Ryan White CARE Act guidelines by Medicaid and MCOs.

6.2 Annually publish a directory of HIV specialists in the District, including availability, on the D.C. Department of Health website.

VII. APPENDICES

APPENDIX A

A.1 Insert – Demographics and eligibility of all HIV+ D.C. Medicaid clients during FY1998 (page 13-4)

The following tables show the percentage utilization of health care and support services by 7,383 clients. The services are provided by a multitude of providers, including but not limited to, major teaching institutions, community hospitals, community health centers, known HIV centers, and safety net providers.

Table A.2. Health Care Services 2001

Service Utilization Reports, 2001	
HIV Health Care Services, District of Columbia	
Services	% of clients utilizing services (N =7788)
Ambulatory/outpatient medical care	38%
Dental care visits	7.3%
Mental health therapy/counseling	7.6%
Substance abuse treatment/counseling	5.2%
Emergency drug assistance	12%
Nutritional services	24%
Treatment adherence/compliance	14%
Title I Case management	25%
CBC funded case management	1.5%
Title: Discharge Planning	3.5%

Source: *URS Report extracted from Metrocares, DC 2001*
HIV/AIDS Administration, DOH

Note: The % is not additive; these service areas are not mutually exclusive.

Service Utilization Reports, 2001	
Support Services, District of Columbia	
Services	% of clients utilizing services (N =7788)
Client Advocacy	4.4%

Day/Respite care	1.0%
Emergency Financial Assistance	18%
Home Delivered Meals/Groceries	13%
Food Bank	62%
Housing Assistance	4.0%
Transportation	5.2%
Complimentary Therapy	15%
Case Finding	25%
Interpreter Services	1.4%

Source: *URS Report extracted from Metrocares, DC 2001*
HIV/AIDS Administration, DOH

Note: The % cannot be added to 100% due to duplication of patients across services.

Note: Summary of results being worked on. Will be ready by tomorrow, pm.

Quality Improvement Review, 2001[i]	
Program Review: CBC funded services (N = 5 providers; 3 from DC)	
Selected Indicator	Compliance Level
Completed medical history by second visit	100%
Complete physical exam by second visit	95%
Documentation of HIV infection	100%
Documentation of cause of HIV infection	82%
Documentation of opportunistic infections	95%
Documentation of appropriate blood tests, x-rays, skin tests, etc	98%
Immunizations: Tetanus Pneumovax Diphtheria Hepatitis B	 15% 71% 9% 78%
PPD skin test	80%
PAP smear for female patients, >12 yrs every 6 mos	21%
Serological test for syphilis/other STDs once a year	74%
Hepatitis B profile	93%
Hepatitis C profile	88%
CD4 count every 6 mos	85%
Viral load every 6 mos	86%
Toxoplasma at baseline	93%

Chest x-ray if abnormal PPD	85%
Notations for 2 or more ARV if CD4 = <350 cells/mm^3 or viral load = >50 units/mm^3	100%
Initiation of PCP prophylaxis when indicated	98%
Initiation of MAC prophylaxis when indicated	99%
Routine surveillance & monitoring for OIs	94%

1

Table A.5. HIV versus AIDS Utilization by Service Area 2000

HIV vs. AIDS: Utilization by Service Area		
	HIV+	**AIDS**
97 Surv. Data	67%	33%
97 URS/MetroCares (5,051)	60%	40%
# with data	2,388	1,568
% with no insurance	54%	40%
Demographics:		
Male	65%	77%
Female	35%	23%
Black	86%	82%
White	8%	13%
Hispanic	5%	4%
Other	1%	0
Transmission Data		
MSM	32%	39%
MSM/IDU	4%	5%
M/IDU	13%	17%
F/IDU	9%	7%
M/Heterosexual	22%	12%
F/Heterosexual	22%	12%
Other	2%	3%

[1] [1] Chart review was used to evaluate the provider's consistency in complying with 16 key objectives established using PHS Guidelines during the periods March 1, 2001 – July 31, 2002. Three DC medical service providers funded under the Congressional Black Caucus (now called the Minority AIDS Initiative) were included in this review. The indicators were rated using weighted scores and aggregated for all providers. The minimum threshold used for this review is 75%. Numerous factors interplay in these results that comparability between providers and patients cannot be done. No control group was used in this case; rather the review was done to assess compliance to established protocols.

Pediatrics	4%	4%
Service Area		
Medical	66%	34%
Dental	53%	47%
Mental Health	58%	42%
Substance Abuse	63%	37%
Case Management	59%	41%
Home Health	19%	81%
Hospice	8%	92%
Legal	53%	47%
Nutrition	57%	43%
Day Care	62%	38%
Emergency Fin.	57%	43%
Housing Counseling		
Food	40%	60%
Transport	53%	47%
Foster Care		
Day Treatment	43%	57%
Emergency Drug	60%	40%
Crisis Intervention	63%	37%

Surveillance data based on alive AIDS cases (4,667) and CDC estimates of 2 HIV cases per AIDS case (=9,334 alive HIV). Per CDC, two-thirds of HIV+ cases are aware of their status (=6,160). "AIDS Alive" cases are based on HAA's HIV/AIDS Surveillance Report Update through December 31, 1997, Vol. 18, April 1998.

APPENDIX B

Definition

The CDC issued case definitions of AIDS in 1983, 1985, 1987, and most recently in January of 1993, for purposes of surveillance and reporting. As provided by CDC, the 1993 classification system for "HIV-infected adolescents and adults categorizes persons on the basis of clinical conditions associated with HIV infection and CD4+ T-lymphocyte counts. It is based on three ranges of CD4+ T-lymphocyte counts and three clinical categories, and is represented by a matrix of nine mutually exclusive categories." The categories are defined in the "1993 Revised Classification System for HIV Infection and Expanded Surveillance Case Definition for AIDS Among Adolescents and Adults," as published by the CDC. In essence, the 1987 definition for the classification of AIDS has been expanded to include an individual who has the following:

- a laboratory confirmation of HIV infection and a CD4+ T-Lymphocyte count of less than 200 cells per microliter of blood, or a CD4 + percentage of less than 14

- a laboratory confirmation of HIV infection and one or more of the 23 previously defined clinical conditions, or presents with one of the three newly added AIDS-defining conditions of pulmonary tuberculosis (TB), recurrent pneumonia, or invasive cervical cancer.

APPENDIX C

HIV Specialist Certification Criteria
The following certification recommendations are based on the New York AIDS Institute HIV Specialists Policy. The intent of the organization's policy is "to guide clinical providers and health care facilities in development and implementation of their own procedures for the credentialing of HIV Specialists and to articulate the standards for a statewide definition of an HIV Specialist." Its Medical Care Criteria Committee reached consensus for the need for an experience-driven definition of HIV specialists as well as a process for providers who lack the level of experience to gain it.

In accordance with industry credentialing standards, it is expected that providers be reassessed every two years to determine their compliance with HIV specialist status. The qualifications for HIV specialists are as follows:

- *Physician:* 1) Direct clinical management of persons with HIV as part of a post graduate program, clinic, hospital-based, or private practice during the past two years. Primary ambulatory care of HIV-infected patients should include the management of patients receiving antiretroviral therapy over an extended period of time. This experience should equal 20 patient years of experience. (Twenty patient years of experience may include managing 10 unique patients over two years, 20 unique patients over one year, or 40 patients over a period of six months.) 2) Possess 10 hours annually of continuing medical education that includes information on the use of antiretroviral therapy in the ambulatory care setting.

- *Other Health Professionals:* Nurse practitioners, licensed nurse midwives, and physician assistants may also be considered HIV specialists if they provide clinical care to HIV-infected individuals in collaboration with a physician and provided that they meet other practice agreements as required by District license and regulations governing professionals.

General Expectations for AIDS Specialist
An HIV specialist should have an understanding of and familiarity with the following areas:

- Latest information about the disease and treatment: advances in antiretroviral therapy; data regarding new drugs and their combinations that change standards of practice; familiarity with drugs, including side effects, treatment-related lipid disorders, and interactions with other drugs.
- State of the art diagnostic techniques: quantitative viral measures and resistance testing.
- Immune system monitoring.
- Strategies to promote treatment adherence: basic familiarity with the clinical presentation and proper diagnostic approach to opportunistic diseases and a strong

grasp of the therapeutic strategies to manage them.

- Management of opportunistic infections and diseases.
- Expertise in the management of HIV-infected patients suffering from commonly associated comorbid conditions, including tuberculosis, hepatitis B and C, and syphilis.
- Access and referral to clinical trials.
- Post-exposure prophylaxis protocols and infection control issues.
- Care coordination: appropriate referral to other providers for specialty care (e.g., oral, ophthalmologic, obstetrics, gynecology, dermatology, nutrition, drug treatment).
- Patient education, including risk reduction/harm reduction counseling.

Specific Expectations of an HIV Specialists in Obstetrics
In addition to the above, an HIV specialist in obstetrics should have an understanding of the following:

- Factors associated with perinatal HIV transmission: including appropriate use of antiretrovirals for prevention of perinatal HIV transmission consisting of antepartum, intrapartum and newborn regimens, as well as the risks, benefits, and indications for cesarean delivery versus vaginal delivery for reduction of prenatal transmission.
- Importance of immune system/viral load monitoring during pregnancy.
- Appropriate use of antiretrovirals for maternal health: including risks and benefits to the fetus and mother.
- Importance of prenatal HIV counseling and testing for pregnant women.
- Collaboration with an HIV Specialist for long-term care of mother.
- District of Columbia regulations regarding counseling and testing, newborn testing, and expedited newborn testing.

Specific Expectations of an HIV Specialists in Pediatrics
In addition to the expectations of the medical specialists, an HIV specialist in pediatrics should have an understanding of the following:

- Factors associated with perinatal HIV transmission: including an understanding that HIV-infected women should not breastfeed.
- Preventive therapy for the newborn to prevent perinatal HIV transmission.
- Diagnostic testing schedule for the HIV-exposed infant: including interpretation

of HIV tests in the newborn, appropriate diagnostic tests, and recommended testing schedules.

- PCP prophylaxis guidelines for HIV-exposed and infected infants
- Immune system monitoring: including an understanding of the normal range of CD4 counts in children at different ages.
- Antiretroviral treatment of an HIV-infected infant or child: including timing of initiation, and an understanding of the pharmacokinetics of antiretrovirals in infancy and childhood, appropriate antiretroviral combinations, their side effects, and special adherence issues.
- Regulations regarding newborn testing and expedited testing.
- Immunization schedule for infected infants and infants in homes with HIV-infected person(s).
- Issues related to disclosure of HIV status to children within families and management of HIV-infected children in school and daycare settings.

APPENDIX D

District of Columbia Policies: Individuals with HIV/AIDS

A series of Director's Organizational Orders led to the establishment of what is now the District of Columbia HIV/AIDS Administration (HAA). The first order established an AIDS Program Coordination Office in 1986 (#140 of July 31, 1986). The second established an Office of AIDS Activities (#152 of June 9, 1987). The third created the agency for HIV/AIDS (#219 of December 7, 1993), and the fourth expanded the agency into the Administration for HIV/AIDS (#8 of May 27, 1997). Various policies relating to the treatment of individuals infected with HIV/AIDS have emanated from the Department of Human Services and Council of the District of Columbia since the mid-1980s when this disease was reported in the United States. Following are a partial list of these legislative mandates and Mayoral orders:

- The Director of the Department of Human Services amended Chapter 5, Title 8, District of Columbia Health Regulations to require that all AIDS cases be reported to the Department of Human Services, Commission of Public Health, effective October 7, 1983.

- In 1983, Chapter 20, Title 29 of the D.C. Code of Municipal Regulations was amended to permit financial assistance for payment of health benefit premiums for unemployed persons infected with HIV/AIDS.

- In 1985, the D.C. Mayor, in response to the emergence of AIDS, established the Office of AIDS Activities in the Commission of Public Health. This was later changed by a DHS director's organizational order to the Agency for HIV/AIDS.

- D.C. Act 6-123, effective December 30, 1985, The AIDS Health Care Response Emergency Act of 1985, gave the Mayor the power to deal with the emergence of HIV/AIDS. This authority was later delegated to the director, Department of Human Services on March 1986. With the organization of the Department of Health (DOH), this authority was delegated to the DOH director in April 2000.

- D.C. Act 6-156 of April 1986 required the Mayor to develop a comprehensive AIDS health-care response plan to investigate the need to establish a residential health care facility for AIDS patients and to establish an AIDS Program Coordination Office.

- D.C. Law 7-189, The Health Care Decisions Act of 1988, established procedures for making health care decisions on behalf of incapacitated individuals facing terminal illnesses.

- Mayor's Order #88-209 of September 1988 mandated that each government agency should designate an AIDS coordinator responsible for development and implementation of an AIDS education plan of action within the agency.

- In 1989, the Board of Education made several rules to amend Chapter 10, of Title 5, of the D.C. Municipal Regulations, to establish procedures governing the school system's conduct/response to employees/students with communicable diseases including HIV/AIDS.

- D.C. Law 7-208, effective March 16, 1989, amended the Prohibition of Discrimination in the Provision of Insurance Amendment Act of 1988. The 1989 amendment permitted life insurance companies to request an HIV/AIDS test of any individual applying for life insurance. It also specified the conditions of the test, informed consent, strengthened confidentiality requirements and revised penalty provisions for breach of confidentiality.

- The director of DHS adopted a new Chapter 20 of Title 29, DCMR to govern the District of Columbia's program to assist low income district residents diagnosed with HIV/AIDS, in meeting the cost of prescribed drugs approved by the FDA. This was effective June 13, 1989.

- D.C. Act 8-284, the Real Estate Transaction Amendment Act of 1990, amended the D.C. Real Estate Licensure Act to discourage discrimination against owners and occupants of real property, including individuals infected with HIV/AIDS. It was effective December 14, 1990.

- D.C. Act 9-299, effective November 23, 1993, provided that following death, the medical certification of cause of death be restricted from distribution unless specifically requested by family members, legal representatives, insurers, and other official representatives.

- D.C. Act 9-252, effective March 25, 1993, amended the Drug Paraphernalia Act of 1982 to provide an exemption for hypodermic syringes and needles, which are distributed by the Commission of Public Health as part of a defined needle exchange program.

- The director of DHS adopted a policy for the placement of HIV-infected children with childcare providers from whom the Department procured services. This policy was effective January 1993.

- In 1993, the D.C. Commission of Public Health, following the guidelines issued by the CDC in July 1991, developed and published guidelines for preventing transmission of HIV and Hepatitis B virus to patients during exposure-prone invasive procedures.

- The HIV Prevention Community and Planning Committee was formed in May 1994 to address the prevention needs within the District of Columbia in relation to the HIV/AIDS epidemic. The committee identifies and prioritizes prevention

needs and allocates funding.

- In 1995, the Commission of Public Health developed a series of policy initiatives to reduce the perinatal transmission of HIV, suggesting that all adults and adolescents, especially pregnant women, receive HIV counseling and testing as part of their comprehensive medical care.

- D.C. Act 11-101, effective March 22, 1996, amended the Drug Paraphernalia Act of 1982 to allow qualified community-based organizations or other qualified individuals, specifically designated by the Commission of Public Health, to exchange needles and syringes under the Needle Exchange Program in the District of Columbia.

- In August 26, 1997, the Mayor ordered the establishment of the District of Columbia Community HIV/AIDS Advisory Committee as well as appointed 40 public members to it.

- In 1991, and again in 1997, in response to legislation authorizing the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act of 1990 and 1996, as well as establishing the Washington Eligible Metropolitan Area (EMA), the Mayor appointed District of Columbia representatives on the Washington Regional HIV Planning Council.

- The HIV/AIDS Advisory Committee order was revised through the Mayor's Order 99-140, September 1999, to serve as an advisory committee to the AIDS Drug Assistance Program.

APPENDIX E

DETAILED YEAR-BY-YEAR PROJECTIONS

	2000				2001			
Type of Service	HIV (service units)	HIV (n)	AIDS (service units)	AIDS (n)	HIV (service units)	HIV (n)	AIDS (service units)	AIDS (n)
Primary Medical Care	10,159	3,258	5,233	1,069	11,581	3,714	5,965.94	1,219
Dental Care	707	3,258	627	1,069	806	3,714	714.76	1,219
Mental Health	5,133	3,258	3,717	1,069	5,852	3,714	4,237.38	1,219
Substance Abuse/Therapy/Counseling	6,262	3,258	3,678	1,069	7,139	3,714	4,192.69	1,219
Case Management	2,850	3,258	1,694	1,069	3,249	3,714	1,930.83	1,219
Day/Respite Care	86	3,258	52	1,069	98	3,714	59.78	1,219
Food Bank/Home Delivered Meals	400	3,258	600	1,069	456	3,714	684.00	1,219
Transportation Services	132	3,258	117	1,069	150	3,714	133.41	1,219

	2002				2003			
Type of Service	HIV (service units)	HIV (n)	AIDS (service units)	AIDS (n)	HIV (service units)	HIV (n)	AIDS (service units)	AIDS (n)
Primary Medical Care	13,144	4,216	6,771	1,383	14,853	4,764	7,652	1,563
Dental Care	915	4,216	811	1,383	1,034	4,764	917	1,563
Mental Health	6,642	4,216	4,809	1,383	7,505	4,764	5,435	1,563
Substance Abuse/Therapy/Counseling	8,103	4,216	4,759	1,383	9,156	4,764	5,377	1,563
Case Management	3,688	4,216	2,191	1,383	4,168	4,764	2,476	1,563
Day/Respite Care	111	4,216	68	1,383	125	4,764	77	1,563
Food Bank/Home Delivered Meals	518	4,216	776	1,383	585	4,764	877	1,563
Transportation Services	171	4,216	151	1,383	193	4,764	171	1,563

	2004				2005			
Type of Service	HIV (service units)	HIV (n)	AIDS (service units)	AIDS (n)	HIV (service units)	HIV (n)	AIDS (service units)	AIDS (n)
Primary Medical Care	16,784	5,383	8,646	1,766	18,882	6,056	9,727	1,987
Dental Care	1,168	5,383	1,036	1,766	1,314	6,056	1,165	1,987
Mental Health	8,481	5,383	6,141	1,766	9,541	6,056	6,909	1,987
Substance Abuse/Therapy/Counseling	10,346	5,383	6,076	1,766	11,640	6,056	6,836	1,987
Case Management	4,709	5,383	2,798	1,766	5,298	6,056	3,148	1,987
Day/Respite Care	141	5,383	87	1,766	159	6,056	97	1,987
Food Bank/Home Delivered Meals	661	5,383	991	1,766	743	6,056	1,115	1,987
Transportation Services	218	5,383	193	1,766	245	6,056	218	1,987

	2006				2007			
Type of Service	HIV (service units)	HIV (n)	AIDS (service units)	AIDS (n)	HIV (service units)	HIV (n)	AIDS (service units)	AIDS (n)
Primary Medical Care	21,242	6,813	10,943	2,235	23,791	7,630	12,256	2,504
Dental Care	1,478	6,813	1,311	2,235	1,656	7,630	1,468	2,504
Mental Health	10,733	6,813	7,772	2,235	12,021	7,630	8,705	2,504
Substance Abuse/Therapy/Counseling	13,095	6,813	7,690	2,235	14,666	7,630	8,613	2,504
Case Management	5,960	6,813	3,542	2,235	6,676	7,630	3,967	2,504
Day/Respite Care	179	6,813	110	2,235	200	7,630	123	2,504
Food Bank/Home Delivered Meals	836	6,813	1,255	2,235	937	7,630	1,405	2,504
Transportation Services	276	6,813	245	2,235	309	7,630	274	2,504

VIII. REFERENCES

Begley S, G. Cowley, D. France, and L. Clemetson. 2001. *Special Report: AIDS at Twenty.* Newsweek Magazine, June 11, 2001.

Berwick, D.M. 2001. We All Have AIDS. *The Washington Post.* June 26, 2001.

Centers for Disease Control. January 2001. *HIV Prevention Strategic Plan Through 2005*. Washington, D.C.

Centers for Disease Control. 2001. HIV/AIDS Surveillance Report., Volume 13, #2. Year End Edition. Department of Health and Human Services, Washington, DC.

Centers for Disease Control. June 1998. Recent HIV/AIDS Treatment Advances and the Implications for Prevention. CDC Update. Department of Health and Human Services, Washington, DC.

D.C. Department of Health. June 2000. Division of Epidemiology Presentation for Ryan White Jurisdictional Data Report. Trends and Findings 1988 through 1999.

D.C. Department of Health. October 1999. *District of Columbia HIV Counseling and Testing Policy*. HIV Prevention Plan: Section 4.203.

D.C. Department of Health. October 1999. *District of Columbia HIV Specialist Policy*. HIV Prevention Plan: Appendix I.

Gray S., and A. Goldstein. 2001. Gay Blacks in Denial About HIV, Groups Say. *The Washington Post* (Metro Section) June 3, 2001.

Health Resources and Services Administration. 1998. Ryan White CARE Act Data: Title II Client Report, Grantee (State): District of Columbia. Retrieved from the World Wide Web, June 15, 2001, at http://hab.hrsa.gov/Data/habquery/1998/report98.cfm.

Health Resources and Services Administration. December 18, 1998. HHS Fact Sheet: The Ryan White Comprehensitve AIDS Resources Emergency (CARE) Act. Retrieved from the World Wide Web, June 13, 2001 at http://www.os.dhhs.gov/news/press.

Health Resources and Services Administration. September 1999. HIV/AIDS Evaluation Monograph Series: A Practical Guide to Evaluation and Evaluation Terms for Ryan White CARE Act Grantees. Washington, D.C., U.S. Department of Health and Human Services.

Health Resources and Services Administration. The Ryan White CARE Act. Summary of provisions, services, funding, and issues relating to this legislation retrieved from the World Wide Web on June 15, 2001, at http://hab.hrsa.gov/ryan/rwhite/rwhite.html.

Health Resources and Services Administration: Office of Science & Epidemiology, HIV/AIDS Bureau. 1999. Trends in the Composition of Ryan White CARE Act Title I Comprehensive Health Services Planning Councils: 1993-1997.

HIV/AIDS Administration DCC Presentation. July 18, 2001. Washington, D.C. Eligible Metropolitan Area: Service Utilization Profile: District of Columbia.

Medical Assistance Administration. 2001. HIV/AIDS and Medicaid in the District of Columbia: Briefing Documents Washington D.C., Department of Health.

Metropolitan Washington Regional HIV Health Services Planning Council. 2001. 2001 Client Survey and 2001 Provider Survey: Major Findings. District of Columbia, July 11, 2001.

Ormond B., L. Blumberg, J. Holahan, D.G. Stevenson, S. Wallin, and J.M. Wiener. 1999. *Health Care for Low Income People in the District of Columbia*. Washington, D.C.: The Urban Institute.

Raspberry, R. 2001. Getting a Grip on AIDS. *The Washington Post.* June 22, 2001.

United Nations Joint Program on AIDS (UNAIDS) 2001. AIDS Epidemic Update. December 2002. UNAIDS, Geneva, Switzerland.

University of California and the San Francisco AIDS Foundation. May 4, 1998. *Policy/Communications Counterparts Briefing on the HIV Costs Services and Utilization Study (HCSUS).*

Wurzbacher & Associates for the D.C. Care Consortium. 1999. Five-Year Housing and Supportive Service Plan for People Living with HIV/AIDS in the District of Columbia, 1999-2004.

IX. GLOSSARY

A.A.M.R.	American Association on Mental Retardation. The nations oldest and most respected professional society concerned with mental retardation.
A.B.S.	Adaptive Behavior Scale. The A.B.S. is one of the best-researched and tested psychological measurement tools for evaluating adaptive behavior (daily functioning).
A.D.A.	The federal Americans with Disabilities Act of 1990.
ABI	Acquired Brain injury.
ADL	Activities of Daily Living. Routine activities carried-out for personal hygiene and health (including bathing, dressing, feeding) and for operating a household.
Advocacy	Parents (or families), organizations or volunteers working on behalf of the rights and interests of others (such as people with disabilities)
Affect	The observable emotional condition of an individual at any given time.
Affective Disorders	Mental illnesses characterized mainly by abnormalities in mood. The two principal categories are mania and depression.
AIDS	Acquired immune deficiency syndrome
Amputation	The removal, usually by surgery, of a limb or organ.
Arthritis	Inflammation of a joint, usually accompanied by pain and swelling and sometimes changes in structure.
Attention, Alternating	The ability to move attention appropriately from one area to another. It requires directional control, as well as capacity.
Attention/ Concentration	The ability to focus on given task or set of stimuli for an appropriate period of time.
Baseline	The frequency or duration that a behavior occurs before it is changed, modified or before a program is put into place.
C.A.R.F.	Commission on Accreditation of Rehabilitation Facility. A private non-profit organization that establishes standards of

	quality for services to people with disabilities. Adherence to these standards is then measured through an on-site review of the organization. CARF is the nationally recognized accreditating authority whose sole concern is to promote quality services for people with disabilities.